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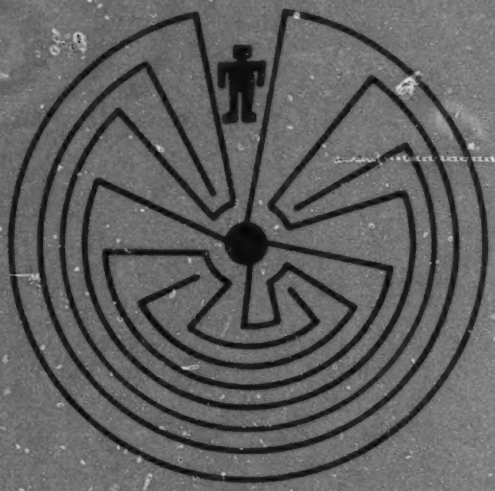
1982 ANNUAL REPORT OF THE NATIONAL ARTHRITIS ADVISORY BOARD



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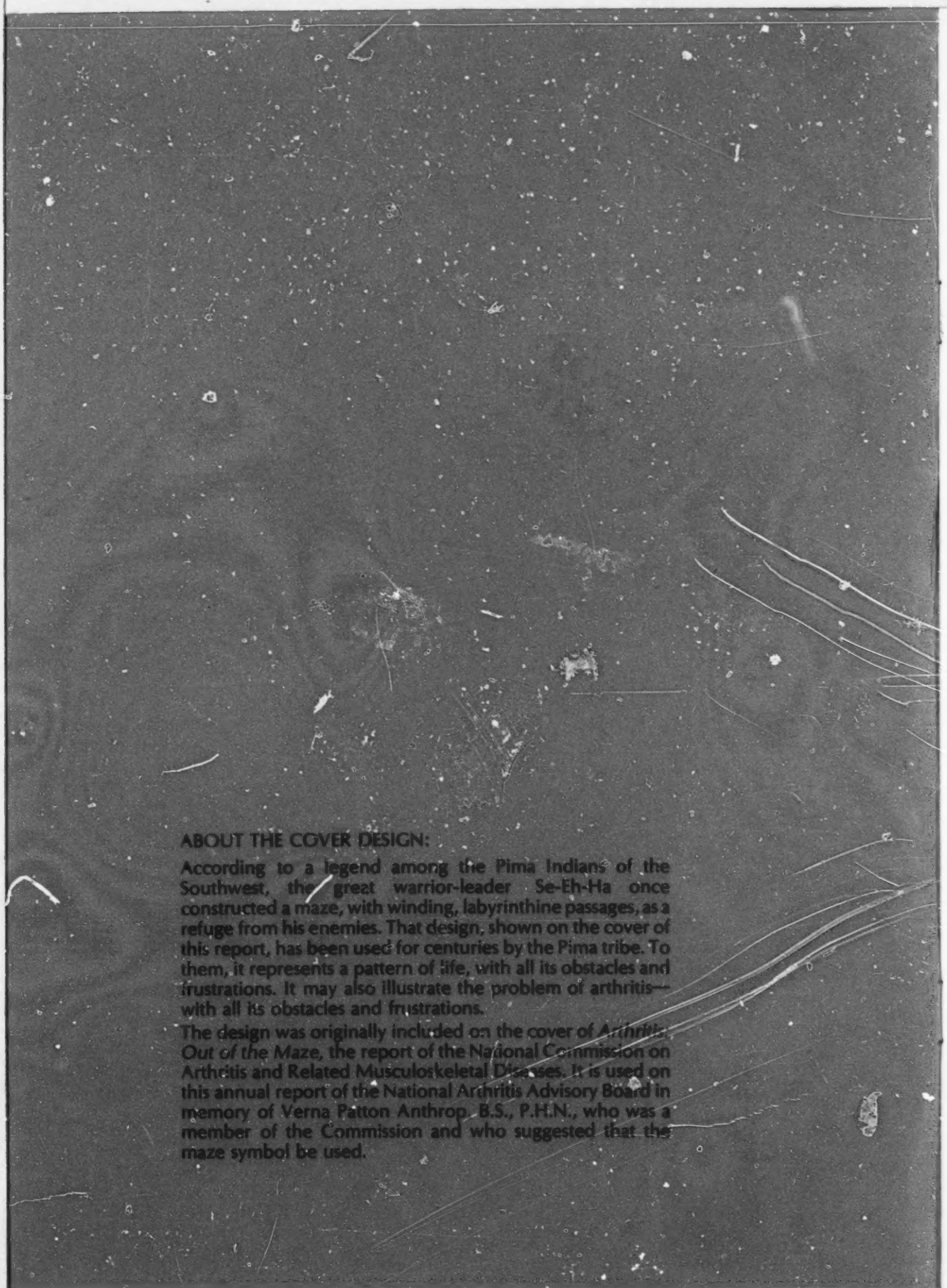

ABOUT THE COVER DESIGN:

According to a legend among the Pima Indians of the Southwest, the great warrior-leader Se-Eh-Ha once constructed a maze, with winding, labyrinthine passages, as a refuge from his enemies. That design, shown on the cover of this report, has been used for centuries by the Pima tribe. To them, it represents a pattern of life, with all its obstacles and frustrations. It may also illustrate the problem of arthritis—with all its obstacles and frustrations.

The design was originally included on the cover of *Arthritis: Out of the Maze*, the report of the National Commission on Arthritis and Related Musculoskeletal Diseases. It is used on this annual report of the National Arthritis Advisory Board in memory of Verna Patton Anthrop, B.S., P.H.N., who was a member of the Commission and who suggested that the maze symbol be used.

1982 ANNUAL REPORT OF THE NATIONAL ARTHRITIS ADVISORY BOARD

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES
Public Health Service
National Institutes of Health
NIH Publication No. 82-2481
July 1982

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The Honorable George Bush
President of the United States Senate
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Washington, D.C. 20510

Dear Mr. President:

In accordance with Section 440(j) of the Public Health Service Act, the National Arthritis Advisory Board is pleased to submit a report covering the activities of the Board with specific reference to the implementation of the Arthritis Plan.

The current Board has only been in operation since October 1981. Consequently, this report is brief. Although much progress has been made in implementing the Arthritis Plan, the Board feels that there are pressing issues that need to be addressed and major needs that remain unmet. These are discussed in the report, along with the Board's recommendations for action.

The Board hopes that this report will be useful and informative and will spur further efforts to fulfill the Plan's recommendations.

Respectfully,

James R. Klinenberg, M.D.
Chairman

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The Honorable Thomas P. O'Neill, Jr.
Speaker of the House of
Representatives
Rayburn House Office Building
Washington, D.C. 20515

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The Honorable Richard S. Schweiker
Secretary, Department of Health
and Human Services
200 Independence Avenue, S.W.
Washington, D.C. 20201

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Respectfully,

James R. Klinenberg, M.D.
Chairman

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WILLIAM E. PLUNKETT
Executive Director

PREFACE

Arthritis, in its more than 100 forms, is both a crippler and a killer. It is well-known that 35 million Americans—about 1 in 7, or 15 percent of the population—suffer from arthritis and related musculoskeletal diseases. Included are not only rheumatoid and osteoarthritis, the two more common forms, but also other important conditions of systemic lupus erythematosus, scleroderma, ankylosing spondylitis, juvenile arthritis, and many other equally debilitating diseases.

Previous estimates compiled by the National Center for Health Statistics and other sources of the costs resulting from various diseases rank arthritis and related musculoskeletal diseases as second in overall adverse impact among all American citizens. These estimates also project that in the year 2000, expenses attributed to arthritis will consume 4.6 percent of the total health outlay, or approximately $96.8 billion. As the Nation's number one crippler, arthritis is also responsible for an increasing number of persons leaving the work force before attaining normal retirement age. The resultant loss of earnings is staggering; current estimates place this figure at $25 billion a year.

Contrary to popular belief, arthritis is not just a disease of old age. Although it affects more than 40 percent of people over age 65, arthritis can strike people in any age group. Estimates are that 250,000 children under 18 have arthritis or a related joint disease, and 100,000 of these children will carry crippling handicaps into their adult years. Some forms of juvenile arthritis can cause crippling of limbs, kidney disease, blindness, and even premature death. Arthritis affects women twice as often as men, and it is most prevalent among low-income and rural populations. Since the Nation's elderly citizens are expected to increase from 10 percent to 20 percent of the total population by the year 2030, the prevalence of arthritis can be expected to increase as well.

The Arthritis Plan, developed by the National Commission on Arthritis and Related Musculoskeletal Diseases in April 1976, contained approximately 145 recommendations designed to systematically attack the problems associated with arthritis. The plan contains an analysis of major areas such as research, education and training, data systems and epidemiology, arthritis centers, and community programs, along with appropriate budget recommendations for these areas. Many of the plan's recommendations have been successfully carried out. Action on many of the other recommendations, however, has been minimal or has not begun, principally because of budgetary restrictions.

Among the Commission's recommendations was a proposal to create the National Arthritis Advi-

sory Board (NAAB). In October 1976, Public Law 94-562 officially established the Board, and in 1980, Congress renewed the Board's authorization. An ongoing function of NAAB is to review and evaluate the effectiveness of the Arthritis Plan, and to take action to amend the plan when appropriate. The present Board consists of 25 members, who are drawn from the public and private sectors, with representation from the medical and surgical disciplines as well as the related health fields and from the general public. The Board is divided into five subcommittees that address various aspects of the Arthritis Plan. The subcommittees are:

- Research
- Epidemiology/Data
- Multipurpose Arthritis Centers (MAC's)
- Education and Training
- Community Programs and Rehabilitation

To maintain cohesiveness and to carry out its monitoring activities, the Board meets as a whole not less than four times a year. In addition, the subcommittees of the Board meet regularly to set directions for their monitoring activities.

SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

While much remains to be accomplished before the pain and disability of arthritis can be totally prevented or cured, research advances are already brightening the picture for many arthritis sufferers. In the area of drugs, researchers are continuing to study the action of anti-inflammatory agents that can reduce some of the pain and swelling that often accompany joint diseases. They are also working with drugs that can suppress the body's immune responses, which in certain joint diseases are injurious rather than protective. The key in such research is to identify drugs that help the patient without producing serious side effects. In addition to finding new ways to help arthritis sufferers with drugs, scientists are refining their knowledge and use of artificial implants that can replace joints damaged or destroyed by arthritis. Such joint replacements can eliminate pain and restore mobility to arthritis sufferers who otherwise might be bedridden.

Since the causes of most rheumatic diseases remain elusive, there is a need for continuing research to pinpoint and track promising leads in the laboratory. There is also a need to identify practical strategies to prevent some of these diseases; for example, it may be possible in the future to identify which individuals are at high risk of contracting certain forms of arthritis and help these people to avoid specific forms of activity and occupations which place undue stress on their joints. The Board is currently planning a national conference on prevention of arthritis and related diseases that will be held during the coming year.

Ultimately, the problem of arthritis and related musculoskeletal diseases will be solved through a combined effort on the part of researchers, clinicians, Federal and community policymakers, administrators, educators, and an aware general public. This combined effort takes money. On April 22, 1982, Richard S. Schweiker, Secretary of Health and Human Services, announced the designation of the National Institute of Arthritis, Diabetes, and Digestive and Kidney Diseases (NIADDK) as a Bureau, with the same status as the National Cancer Institute and the National Heart, Lung, and Blood Institute; he also designated a separate division within NIADDK for arthritis (the Division of Arthritis, Musculoskeletal, and Skin Diseases). This important step signifies Federal recognition of the problems of arthritis and related diseases, since NIADDK is the lead agency funding research on these diseases. Only with appropriate and sufficient funding from Congress now and in the future will the pain, disability, and suffering of arthritis be eliminated (see table 1).

It is the Board's conviction that while a number

of important and significant efforts to implement the Arthritis Plan have begun and progress against these diseases has been made, a great deal remains to be accomplished. Identified needs in a variety of areas—including research, epidemiology, and education and training—remain unmet. The following report outlines progress that has been made in implementing the plan.

Table 1

BUDGET RECOMMENDATIONS FOR FISCAL YEAR 1983
NIADDK ARTHRITIS PROGRAM
(Thousands of Dollars)

Research grants	$68,000	Research and development contracts	3,462
Modernization of equipment and facilities for extramural arthritis research	3,000	Epidemiology	1,000*
Multipurpose Arthritis Centers	12,000	Data	715*
Other research: Research Career Development Awards, Clinical Investigator Awards, data systems research, scientific workshops	4,122	Education and training, conferences, seminars, and workshops	700
National Research Service Awards (training)	4,497	NIH intramural research	7,119
		Arthritis Information Clearinghouse	200†

*Not included in recommendation for research grants.

†In addition to $200,000 currently included in research and development contracts recommendation.

REPORTS OF THE SUBCOMMITTEES

RESEARCH

Research is the keystone of the Arthritis Plan. It is only from new knowledge gained through research that new modes of management of rheumatic diseases can be developed. The National Arthritis Advisory Board is dedicated to the concept that adequate resources for research must be made available to qualified investigators.

In 1976, the Arthritis Plan listed almost 60 recommendations for research. Many of the recommendations and objectives for research have been achieved, while for others no answers are available. New paths to knowledge that have evolved since the plan was formulated in 1976 have opened additional broad areas for investigation.

RESEARCH ADVANCES

Examples of newly gained knowledge investigators have been able to utilize since 1976 include the following:

- The explosion of knowledge and the potential for understanding human biology made possible by development of monoclonal antibodies. These monospecific reagents, available in large quantities and directed against single antigenic determinants, are probes which define cell functions and offer an exciting potential for new directions in diagnosis.
- The technology of recombinant DNA, which enables study of the human gene, giving potential to develop a readable library of human genetic information. Soon, it may be easier for the investigator to determine the DNA sequence that prescribes transcription of nucleotides which direct protein synthesis than it is to decipher the amino acid sequence of these same proteins. Such expertise could be applied to learning the exact structure of antibodies, cellular and connective tissue proteins, and enzymes both in normal individuals and in those with arthritic diseases.
- Integration of the specialties of biomaterials and connective tissue biology, enabling orthopedic surgeons to create new and longer lasting artificial joints. Reconstructive surgery alone has given productivity and pain-free function to many people disabled by arthritis. In doing so, reconstructive surgery in some areas of arthritis has been shown to be cost-effective, an extremely important factor in the current era of escalating costs of medical care.

There are many reasons for this expansion of knowledge. A primary factor has been a simultaneous maturing of the basic disciplines of cell biology and immunology. The integration of new techniques and concepts in these fields with already mature doctrines and tools of biochemistry has provided a stimulus to scientists, who now have the capacity to study rheumatic diseases at a basic molecular level. Studies have shown that submissions of abstracts to rheumatology/immunology sections at scientific meetings have increased more than for other subspecialty sections. The rheumatic diseases and the pathophysiology underlying them are being recognized as fascinating models for cellular, enzymatic, and humoral interactions.

The most important priority for arthritis research in the years ahead can be clearly defined: to responsibly and creatively exploit the techniques and assays available to study basic causes of diseases and to discover better modes of therapy for them.

One of the continuing challenges to researchers in arthritis and related diseases will be to integrate data among different disciplines, taking information gathered in one sphere and applying it to another.

CURRENT NEEDS FOR ARTHRITIS RESEARCH

1. Adequate Funding Levels for NIH Grants

Limitation of funding, which guarantees support only to those researchers with grant applications in the top 10 to 20 percent of those approved by peer review groups, harms the research effort. Morale is lowered in the scientific community each time a worthy application is not funded. For the third consecutive year, funding of arthritis and musculoskeletal programs at NIADDK has been at levels well below those recommended by the National Arthritis Advisory Board. It normally takes years to develop efficient research teams, and when minimal sustaining support is withdrawn, their momentum is lost. Refunding in a subsequent year is rarely sufficient to regain that lost momentum.

It is important to focus on expenditures for research by NIADDK, because 65 percent of research funds for arthritis and related diseases originate from this Institute. NIADDK's operating budget for its arthritis division for 1982 is $71,877,000, approximately $1 million less than the $72,326,000 operating budget for 1981. These figures do not take into account the inflation rate, which makes the 1982 funding loss greater.

The cuts in 1982 funding, in addition to making it far more difficult for qualified investigators to receive funds for grants, have necessitated across-the-board cuts in existing, already funded grants (3½ percent cuts in individual research grants, 7 percent cuts in center grants).

This low funding level has resulted in fewer and fewer scientifically meritorious research projects being funded. Between 1975 and 1980, a priority score of 200 or below (indicating support for all of the details of the application by the reviewers, including the budget) assured funding for a grant application submitted to NIH. Even with this funding level, more than 50 percent of the applications approved by peer review were not funded. During fiscal year 1982, only between 20 and 30 percent of approved grant applications will be funded.

The entire scientific profession suffers as funding levels approach as little as one-quarter of those previously funded. Experienced investigators must slash productive programs, and many investigators are increasingly spending more time writing and rewriting grant applications than they are on active research. Academicians and future teachers are not entering the system to begin their apprenticeship for leadership roles.

Based on minimal estimates of the need for fiscal health of research in NIADDK's arthritis program, the Board proposes that the Congress take steps to guarantee stable, responsible funding.

Focusing only on research grants for individual investigators (excluding centers and training grants), expenditures in 1982 ($46,237,000) will be less than those in 1981 ($47,869,000), despite a 9 to 10 percent inflation rate. The President's 1983 budget for research projects planned by the Administration is $46,984,000 (including a reduction of 3 percent in *all* awards plus a 10 percent reduction in indirect costs). This means that only approximately 18.4 percent of approved grants would be funded.

The Board recommends, therefore, that for fiscal year 1983, sufficient money be infused to fund at least 45 percent of approved grants. To do this, approximately $21 million in additional funds will be needed, for a total of $68 million.

2. Refurbishing the Equipment and Facilities for Arthritis Research: An Essential Capital Investment

Realizing that no successful industry continues to compete without capital reinvestment to modernize equipment and facilities, the Board recommends that an additional allocation for such modernization be added to the research grant funds. Most of the laboratories that are conducting research in NIADDK's Division of Arthritis, Musculoskeletal and Skin Diseases were built and equipped more than 10 years ago. Maintenance costs for outdated equipment are skyrocketing. Successful competing applications for research projects often have equipment requests deleted in order to leave high priority budgets for personnel and supplies relatively intact. This trend cannot continue, since good scientists need modern equipment.

The same statement applies to facilities, particularly animal housing and radioisotope disposal programs, which have been subjected to appropriate yet stringent regulations. At a time when indirect costs are being cut, universities cannot afford to rebuild or modernize these facilities.

Therefore, the Board recommends that funds to supplement research grants totaling at least $3 million (less than 5 percent of the requested amounts for research projects) be allocated for replacement of outdated, inefficient laboratory equipment and for upgrading of essential support facilities.

3. Increased Opportunities for Young Investigators

Outstanding scientists come only from a basic support system that provides adequate support for development along with some guarantee of career stability. Funds for research training, which include postdoctoral fellowships, Clinical Investigator Awards, and Research Career Development Awards, must be increased to match the growing number of researchers interested in arthritis-related research projects, and the stipends must be increased to balance the effects of inflation.

Lack of career stability is a major factor leading to a reduction in the number of young investigators who choose careers in academia. Young scientists are moving away from competitive research opportunities because the odds against their being funded are so strong.

The Board recommends, therefore, that the President's budget for fiscal year 1983 for career development awards and other related categories be increased from $3,245,000 to $4,122,000. Similarly, funds to support new investigators who are seeking preliminary training should be increased from $3,686,000 to $4,497,000.

4. Clinical Trials: Research and Development Contracts

Development of new concepts of the pathophysiology of disease and new modes of treatment cannot benefit patients without clinical trials of well-tested modes of therapy under controlled conditions. NIADDK has supported cooperative trials through the contract mechanism. The Cooperative Systematic Studies of Rheumatic Diseases and other contracts have been established and organized to coordinate multicenter controlled trials. The Cooperative Clinics program is well-developed and is assessing the methodology of evaluating clinical trials as well as the effects of specific drugs on the connective tissue diseases. This system should not be allowed to collapse.

The Board recommends that the President's fiscal year 1983 budget of $2,532,000 for research and development contracts for NIADDK's Division of Arthritis, Musculoskeletal, and Skin Diseases be increased to $3,462,000.

5. Intramural NIH Program

Since the formation of NIADDK in 1949, arthritis research within the Institute has been led by investigators on the NIH campus in Bethesda. NIADDK's intramural program has been an important factor in the training of young investigators; its unique research environment leads to studies that are difficult or impossible to do elsewhere.

The product of NIADDK's intramural efforts has been an innovative research program that has given leads and direction to many university-based programs. For example, NIADDK's intramural program has supported extensive research on the immunogenetics of systemic lupus erythematosus (SLE), the treatment of rheumatoid arthritis by immunosuppressive drugs, and the basic defects in heritable connective tissue diseases.

Sustained growth of NIH intramural laboratory and clinical research must be guaranteed. Therefore, the Board recommends an increase in funding for intramural programs from a budget of $6,356,000 in 1982 to $7,119,000—an increase of 12 percent.

6. Veterans Administration

The Veterans Administration hospitals are an integral and important component of the academic teaching and research programs of almost every major university. Traditionally, they have provided a superior training and performance arena for many excellent physician-scientists. To maintain this resource, the Board recommends a 10 to 15 percent increase in research support in arthritis during fiscal year 1983 by the Veterans Administration.

7. Evaluation of Current Arthritis Research

The ongoing evaluation of the musculoskeletal program of the Division of Arthritis, Musculoskeletal, and Skin Diseases is being followed with great interest by NAAB. It may be that a similar study of the arthritis program should be considered which would build on the experience of the present study. Although the peer review system provides strong guarantees that only good research is approved, there is no mechanism at present for assessing the interrelationship of separate arthritis research projects. The Board recommends, therefore, that a process for evaluation be developed.

The objectives of this program should be:

- To define the broad objectives of research in arthritis-related fields.
- To define accomplishments of the research program.
- To point out potential areas for synergistic, collaborative research and to identify areas of unnecessary overlapping.
- To identify areas of high program relevance for future study.
- To prepare a report on evaluation of arthritis research appropriate for distribution to both scientific and lay audiences.

8. Enumeration and Assessment of Research Relative to the Arthritis Plan Being Carried Out in Institutes Other Than NIADDK

Thirty-five percent of arthritis-related research is carried out by Institutes other than NIADDK. This research represents programs that are basic to the success of the Arthritis Plan and must be supported and encouraged by NAAB and NIADDK. In particular, basic investigations at a molecular level by researchers studying the immune response, structure, and function of connective tissue macromolecules and the control of cell function by genes will form the basis for much disease-related research in the future. NAAB also recognizes the important contribution of the General Clinical Research Centers supported by the Division of Research Resources.

Therefore, the Board recommends that the NIADDK staff continue to encourage the efforts of the Arthritis Interagency Coordinating Committee (AICC) and study other possible mechanisms for best identifying research applicable to arthritis programs in other Institutes, for encouraging these programs, and for designing ways to transmit awareness of these programs to NIADDK-supported investigators.

MULTIPURPOSE ARTHRITIS CENTERS

From the inception of the Multipurpose Arthritis Centers program in 1977, a total of 25 institutions have received grants to develop innovative research, education, and community programs. The goal of the MAC program has been to demonstrate and stimulate the prompt and effective application of available knowledge for the treatment of patients with arthritis and related musculoskeletal diseases and to develop essential new knowledge.

These programs have had a significant impact on arthritis. Currently, 19 centers are receiving funds. Evaluation of the activities of the MAC's has been improved greatly by creation of a standing Arthritis Centers Review Committee to consider new and renewal applications. This was a recommendation made by the Board in its 1978 and 1979 annual reports. This committee reviews new and renewal applications from the established centers. Sufficient time has now passed for the Board to comment on the impact that the MAC's have had on the major problems that confront patients, their families, and the professionals who must deal with arthritis and the related diseases. It is with great satisfaction that the Board can report that the MAC's have made and continue to make key contributions in the following areas.

RESEARCH ACTIVITY

More than 40 pilot research projects are currently augmenting the total investigative effort in the

field. The role of infectious agents (viruses and bacteria) in causing inflammatory forms of joint disease is being studied in several ways, while the genetics of the major arthritic disorders continues to be examined in greater detail. The biochemistry of joint cartilage as it relates to the most common arthritic disease, osteoarthritis, is the subject of several research projects. Examination of cellular and humoral immune mechanisms as they affect arthritis and related disorders is strongly represented in the spectrum of research topics supported by center funds. Assessment of drug therapy and other treatment modalities (including surgical joint replacement) is also strongly represented in the MAC's pilot research programs. It is especially noteworthy that two of the centers have taken a leading role in the evaluation of lymph node irradiation as an experimental form of treatment for rheumatoid arthritis and systemic lupus erythematosus.

EDUCATION AND TRAINING PROGRAMS

One of the major goals of the National Arthritis Act was to expand and improve education of patients, their families, and health professionals in all aspects of the arthritis problem. A broad range of programs in this area is offered by all of the centers. Evaluation of different means of improving patient and family education is being accomplished. Education of all health professional groups who participate in the care of the patient afflicted with arthritis is receiving special emphasis in these centers. Assessment of public education as it pertains to the problem of quackery and unproven remedies is being accomplished at several MAC's. Other innovative projects include videotape and computer-assisted educational programs, use of patient instructors and peer-designated professional educators to instruct and train other health professionals, and special efforts to improve professional education pertinent to juvenile arthritis.

COMMUNITY PROGRAMS AND HEALTH SERVICES RESEARCH

Several education programs are aimed at patients and professionals in the community setting. Pilot epidemiological studies are under way in several MAC's. The outcome of juvenile arthritis, the cost-effectiveness of total joint replacement, and analyses of disability in rheumatoid arthritis and osteoarthritis are important examples of community-based MAC projects. It is pertinent to note that methodologies for these may be excellent prototypes for the analysis and study of other forms of chronic disease. The community-based MAC projects have stimulated interaction with local and State health care agencies and have brought to their attention the problems related to arthritis and allied diseases.

STRENGTHS OF THE MAC PROGRAM

As an additional measure of the strengths and success of the MAC programs, the Board notes that the 20 MAC's funded during fiscal year 1981 (total MAC funds amounted to $7.03 million) received additional Federal and non-Federal research support at the level of $17.03 million. Of this total, $11.5 million (68 percent) represented additional competitive research project funding from the National Institutes of Health; $2.02 million (12 percent) came from other Federal sources (National Science Foundation, Veterans Administration); $1.06 million (6 percent) from the Arthritis Foundation; and $2.45 million (14 percent) from other non-Federal agencies or foundations. These data should be considered minimal figures for each funding source. The non-MAC-derived research support in fiscal year 1981 was 2.5 times ($7.03 million versus $17.03 million) the total level of MAC funding. As noted above, the MAC's are also the nucleus for several types of non-Federal (private, foundation, State) research support as well. Another measure of MAC scientific productivity was documented by an informal survey of the origin of papers presented at the 1981 annual meetings of the American Rheumatism Association and the Arthritis Health Professions Association. This survey indicated that more than one-third of the total scientific presentations at these meetings came from these arthritis centers.

FUNDING RECOMMENDATION

Based upon this record of achievement, the Board recommends that Congress appropriate $12 million in support of MAC programs for fiscal year 1983. This would provide for appropriate levels of funding for approximately 21 MAC's during 1983 and allow for modest sustained growth in center funding. The MAC record to date justifies this recommended increase and takes into account

the conservative levels of appropriation for MAC's authorized between 1977 and 1982. These funds have met some of the totals set forth in the National Arthritis Act of 1976. The MAC's will remain an important resource for meeting additional goals in the years ahead.

EPIDEMIOLOGY/DATA

GOALS AND ACTIVITIES

Although the American Rheumatism Association Medical Information System (ARAMIS) data bank (which is discussed specifically in the appendix) currently provides research and information in many areas, it has not had strong epidemiological application. Many of the techniques it has evolved are potentially applicable to epidemiological studies, and efforts to utilize them will be strengthened. ARAMIS is the *only* major data bank initiative in arthritis; it is a carefully monitored prototype system that is testing the components of what may become a model national system for addressing chronic diseases. (See the appendix for the ARAMIS Data Bank Network.)

The National Arthritis Advisory Board also views the epidemiological approaches being developed by a number of Multipurpose Arthritis Centers as representing one effort toward mechanisms for rheumatic disease control. It is believed timely for selected MAC's to review and initiate field tests of several of the assessment instruments developed by ARAMIS and to assess the feasibility for epidemiological applications to selected disorders in geographical areas accessible to the centers.

Establishment of a data program advisory group to review proposed programs leading to a national system also has been partially accomplished. This function is being monitored under the direction of the Program Officer for Epidemiology/Data Systems in NIADDK's Division of Arthritis, Musculoskeletal, and Skin Diseases.

The establishment of arthritis epidemiology units at institutions with well-developed arthritis programs has been encouraged by NIADDK and has been partially implemented since 1977. Also, NIADDK is currently participating in the design of National Center for Health Statistics surveys pertinent to arthritis. Funding is being sought in the 1984 budget for the analysis of survey information relevant to arthritis. NIADDK is also providing partial support for the Health and Nutrition Examination Survey (HANES) Followup Survey.

An Arthritis Epidemiology Conference in September 1980 and two principal publications prepared in conjunction with it were major components of NIADDK's recent efforts to focus attention on, and attract researchers to, initiation of epidemiological studies of the rheumatic diseases. Thirty-eight papers were presented at this international conference by a multidisciplinary group of rheumatologists and epidemiologists. An annotated bibliography, Epidemiologic Studies of the Rheumatic Diseases, and the proceedings from the conference are in the final stages of editing. Distribution of these documents should further stimulate epidemiological activity.

Encouraging progress has been made in the development of data instruments that can assure uniformity in multisite studies of chronic diseases and their societal impact. Dimensions of physical disability, psychological disability, and pain have been demonstrated to exist as surprisingly distinct entities. Widespread application of uniform studies may improve our ability to concentrate scarce resources more productively.

The societal payoff of data banking for long-term illnesses is dependent upon sustained effort and support of the investigators' efforts. Current national trends toward resource restriction can result in an adverse impact upon a relatively modest initiative that cannot be resumed reasonably once continuity is lost.

RECOMMENDATIONS

The Board recommends that the following items be designated for fiscal year 1983 for the NIADDK budget: epidemiology, $1 million; data, $715,000.

ARAMIS was originally funded by NIADDK at less than the approved level. Even with supplemental funding by the National Center for Health Services Research (NCHSR), its approved needs have not been met, and future financial support by NCHSR is uncertain.

Specific programs were recommended in the Arthritis Plan which were specified in the original legislation. Many of these were never funded. It has taken awhile to develop an appropriate climate, but the Board now sees that favorable progress is being made, and worthy applications are now being received.

The funding recommended would allow the initiation of several high-quality projects without compromising existing research.

EDUCATION AND TRAINING

The National Arthritis Advisory Board monitors efforts to develop a better collective understanding of arthritis and related disorders through increased educational or career training opportunities for health professionals, patients, and the general public. The Board has noted the adverse impact of severe budget cuts on the implementation of recommendations in education. In 1979, for example, education received only 30 percent of Multipurpose Arthritis Center funds.

ONGOING PROGRAMS

In spite of funding constraints, the Multipurpose Arthritis Centers have made a significant contribution in professional education and training. Boston University and Indiana University are prototypes for physician education on arthritis and related diseases. Boston University supports an innovative program that trains fourth-year medical students in how to care for homebound and underserved inner-city residents.

Dial-Access System programs in the Alabama Multipurpose Arthritis Center use answer tapes for more than 100 different arthritis-related questions over a toll-free telephone line for rural areas and locations far from a medical center. Stanford University, the University of California at San Francisco, the University of Missouri, and Boston University are using computers in special educational programs.

The Board has noted the progress and growth of the Arthritis Information Clearinghouse since it was established to serve as the focal point for the collection, organization, and dissemination of information concerning professional and patient education materials in arthritis and related musculoskeletal diseases.

Despite these advances, there are many focal areas of concern and unmet needs in the educational and training areas. These are discussed specifically below.

AREAS OF FOCUS

The Board has identified six main focal areas relevant to its goals for education and training:

- Education and training of primary care physicians in arthritis in medical schools, their training in interpersonal relationships in dealing with patients with chronic disease, and their interaction with nurses and allied health professionals.
- Patient and public education and patient advocates.
- Study of the unique problems of the rheumatic diseases of childhood.
- Use and abuse of drugs in the treatment of arthritis.
- Social and behavioral problems of the chronically ill in a home setting as opposed to institutional care.
- A health care system geared overwhelmingly to acute care as opposed to chronic care.

AREAS FOR FURTHER EXPLORATION

In general, primary care physicians see patients with arthritis before other physicians. Physicians in all disciplines may see patients with diseases related to arthritis. Therefore, medical students need to be well-trained in the care of these diseases and the indications for seeking appropriate consultation. At present, there are still some medical schools without a full-time rheumatologist. There is still a need to continue the education of more rheumatologists and other health professionals.

Most nursing and allied health schools do not have arthritis training as a specialty, but depend on their knowledge of arthritis through later experience with arthritis patients. There is a need for continued education and training of nurses, pharmacists, and allied health professionals in the care of patients with arthritis.

PATIENT AND PUBLIC EDUCATION

Although the 1976 Arthritis Plan called for significant expansion of patient, family, and public education in arthritis, allotted funds allowed only modest development of center-sponsored patient and public education programs.

RECOMMENDATION

While the Board recognizes that additional dollars for patient and public education are contained in the budgets of other programs (such as the Multipurpose Arthritis Centers program), the Board recommends that an additional sum of $200,000 be added to the current budget of $200,000 for the Arthritis Information Clearinghouse. This increase will allow the clearinghouse to continue its important work of collecting and disseminating information compiled in both professional and patient materials.

The Board recommends $700,000 be allotted for NIH-sponsored arthritis workshops, seminars, and conferences for continuing education for primary care physicians, nurses, pharmacists, and allied health professionals who treat patients with arthritis.

COMMUNITY PROGRAMS AND REHABILITATION

While no formal federally funded initiatives exist to provide funds for community demonstration projects (as recommended by the National Commission on Arthritis and Related Musculoskeletal Diseases and the National Arthritis Advisory Board), several opportunities may exist for the arthritis community to undertake such projects.

The terms of the NIH-funded Multipurpose Arthritis Centers provide both the opportunity and encouragement to initiate pilot projects and research efforts into selected facets of community programs and services. A second resource may be available in the Independent Living Centers Program, funded by the Rehabilitation Services Administration of the Department of Education. These centers provide a wide range of services for the seriously disabled and are funded in all 50 States. A third potential resource for future funding of community programs is the Administration's Block Grant Program, which makes funds available to the States through the Department of Health and Human Services. A fourth possible source would be private industry, especially emphasizing programs that prevent disability from arthritis in the work force.

The Board is also interested in the provision of Social Security benefits to arthritis patients, as well as in what American industry is doing to keep persons with arthritis employed. The Nation's number one crippler is also responsible for the increasing number of persons leaving the work force before normal retirement age, as indicated by Social Security Administration statistics. The Board has established a working relationship with the Arthritis Foundation in the private sector and, more specifically, with this voluntary agency's Government Affairs Committee, which employs a full-time person to work with the foundation's 73 chapters to increase the use of Federal and State funds to benefit arthritis patients, including the provision of community services and consumer advocacy.

ARTHRITIS IN INDUSTRY

In a 1978 study, the Social Security Administration analyzed data on 12,000 persons chosen from the civilian noninstitutionalized population, ages 18 to 64.* Based on the sample, total population figures were then estimated. The Social Security Administration calculated that 65 percent of the 10.7 million severely disabled adults in this country, or 7 million people, would have a musculoskeletal condition. Severely disabled was defined in this study as working age adults who could not work at all or who could not work regularly. This diagnostic grouping of conditions (which includes arthritis) was repeated far more often than any other condition as interfering with or preventing work.

Obviously, arthritis is—and will continue to be—a major factor in lost time due to the impact of the disease. Some companies, like Burlington Industries, have recognized the critical nature of this problem and have initiated programs designed to reduce the impact of arthritis on the worker and to lengthen the individual's productive life. These pilot efforts, however, only serve to identify a small number of the problem areas.

It would appear that the loss of earnings due to arthritis will remain a major employment problem throughout the remainder of this century. The Board plans to address arthritis in industry during the current year.

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*U.S. Department of Health and Human Services, Work Disability in the United States—A Chartbook, Washington, D.C.: U.S. Government Printing Office, SSA Publication No. 13-11978, December 1980.

APPENDIX—ARAMIS DATA BANK NETWORK

ARAMIS is currently engaged in several dozen active projects. The central unit (core unit) and the major computer resource are based at Stanford University. Ancillary centers (data banks) are dispersed throughout the United States and Canada. Additionally, the Stanford unit provides consultation to the participating data banks in the areas of biostatistics, health care planning, outcome assessment, and computer technology and programming.

The Stanford computer now contains data on 16,381 patients with rheumatologic disorders, representing 91,157 visits, maintained in parallel in the data banks of 14 participating centers. Four new data bank centers joined ARAMIS in 1981.

Much ARAMIS effort has been devoted to software development. Multiple programs have evolved, and new ones are being developed and added as resources allow. The addition of new programs sometimes necessitates modifying old ones for system compatibility and to assure complementary function. The result in these programs for the evaluation of long-term (longitudinal) patient data represents the current state of the art in data banking of medical records for chronic disease.

Increasing emphasis has been directed toward the development and testing of uniform health status instruments that can lend themselves to multiple applications by investigators nationally and internationally. Two such examples are the Health Assessment Questionnaire (HAQ) and the Arthritis Impact Measurement Scale (AIMS). The AIMS instrument has been tested extensively in rheumatoid arthritis. It assesses physical and emotional attributes and has been reapplied to the same patients over 6 months. It appears to be a valid and reliable instrument and after further testing may become an acceptable standard for use in rheumatology and other chronic diseases.

These quests for assessment uniformity utilizing items with known sensitivity and specificity promise significant advancement in the field of health services research, an area which can further the national knowledge base and allow better facts upon which to base decisions in resource allocations. One preliminary application, using the Federal Health Interview Survey (HIS) instrument, has attempted to measure costs of rheumatoid arthritis in a selected community. A total of 18,000 individuals were identified with musculoskeletal complaints, but fewer than 250 had rheumatoid arthritis. The cost findings for rheumatoid arthritis individual patients in the study community were:

Direct Costs:

Hospital care:	$6,083 for average stay of 8 days

Outpatient M.D. visits	259	for average of 9.7 visits/year
Other health care provider costs	95	
Nontraditional treatments	32	
Medications	319	
Lab tests	185	
X-rays	138	
Devices	19	
Miscellaneous	106	(includes $74 for transportation)

The average annual medical costs for all patients in the study with the diagnosis of rheumatoid arthritis was $904.

Indirect Costs

These costs were defined as productive days lost from normal activity due to disability. It compared the expected annual earnings of the general population as stratified by age, sex, and occupation to income actually earned by the subjects during the study year. Homemakers represented 23 percent of the study groups, and the cost for them was calculated as the cost of substituting workers from the local labor market to perform the duties.

At this time, investigation is also under way seeking to compare the effects of use on utilization and costs between fee-for-service and prepaid medical care delivery models such as health maintenance organizations (HMO's). Cooperating rheumatologists are being surveyed prospectively in a stated timespan (using the diary approach) in the San Francisco Bay area.

Work disability, a complex issue of increasing national importance, has been clarified by ARAMIS data. The data indicate that work disability appears to be affected more by the variables of patient age, sex, race, and occupation than by a specific disease or its severity. In rheumatoid patients, for example, only one-sixth of the disability time lost could be accounted for by medical factors. Sixty percent of the patients with rheumatoid arthritis lost some work time. Current analysis indicates a need to seek to coordinate the rhythm of illness to job requirements; in jobs with work-time flexibility, there is less disability time used.

☆ U.S. GOVERNMENT PRINTING OFFICE: 1982- 381-132:724

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NIH Publication No. 82-2481